The implications of traumatic brain injury (TBI) in childhood can be devastating, often resulting in long-term or even life-long disability for the child. The impact of any illness or injury in a child will affect each member of the child’s family in some manner as well. Understanding this impact is important because awareness of family member burdens and needs over time enables health care providers to better support families and address their needs (Stancin, Wade, Walz, Yeates, & Taylor, 2008). Further, because family functioning has been linked to the recovery of the child with TBI (Taylor et al., 1999; Yeates et al., 1997), facilitating family adjustment has the important potential to improve child outcomes.

Wade and colleagues (2010) point out that although TBI shares commonalities with pediatric illnesses, it also differs in several key respects. For example, like cancer, TBI occurs unexpectedly, usually in a previously healthy child, contributing to feelings of vulnerability, anxiety, and loss. TBI differs, however, from most acute and chronic health conditions in its potential long-term impact on the child’s cognition and behavior. TBI also differs from developmental disabilities in that the profile of post-injury abilities may be quite varied, with normal performance in some domains and deficits in others. Additionally, some deficits may be subtle and only noticed over time. Thus, parental distress and coping may vary over time, with distress increasing as awareness of persistent changes grows (Wade et al., 2006).

The serious nature of TBI, along with its implications for parents who play a significant role in providing long-term support for the child, is daunting. Studies have shown that severe pediatric TBI can result in significant distress and burden for parents. This is true in comparison to both families of uninjured children and families of children with injuries not involving the brain. For example, in comparing parental burden and distress for parents of children during the first few months after a TBI with that of parents of children with an orthopedic injury (OI) requiring hospitalization, Stancin and colleagues (2008) found that parents of children with TBI reported greater overall caregiver burden and greater burden related to the injury. Parents of children with severe TBI also reported more stress involving spouses and siblings, and higher levels of parental depression and global distress compared to the OI group.

It is commonly assumed that the majority of parental stressors in managing, adjusting to, and supporting a child’s condition post-TBI results from the child’s impairments and/or the parents’ or the family’s style of coping (Benn & McColl, 2004; Gan, Campbell, Gemeinhardt, & McFadden, 2006; Hawley, Ward, Magnay, & Long, 2003; Wade et al., 2006). However, until relatively recently, little was known about the overall range of parents’ experiences and expectations and their interpretations of the social factors, such as attitudes, beliefs, notions, and expectations, influencing these experiences (Roscigno & Swanson, 2011). Such knowledge can help us evaluate the relevancy of our current practices, services, and existing theories, and identify areas for improvement.

### Describing the Experience

In an effort to learn about the collective range of what parents have to manage, adjust to, or support, Roscigno and Swanson (2011) explored overall experiences of 42 parents whose children were diagnosed with moderate to severe TBI in the first five years following their child’s diagnosis. Parents represented 37 families from 13 states in the United States. Over the course of two interviews, the first conducted four to 36 months following the child’s TBI (M = 15 months) and the second 20 to 48 months post-TBI (M = 27 months), four main themes emerged:

- Grateful to still have my child.
- Grieving for the child I knew.
- Running on nerves.
- Grappling to get what my child and family need.

### Grateful to Still Have My Child

Despite awareness of the seriousness of their child’s situation, parents focused on any positive aspects of their child’s health condition, both initially and over time, as their child began to emerge from the coma (Roscigno & Swanson, 2011). That their child was still alive provided a chance he or she would survive the injury. As the child progressed through later stages of the coma, seeing glimpses of the child they knew gave...
Parents expressed sorrow about their experience, often compounded by a perception that the only conversations many health care providers would enter into were those that ensured parents understood the gravity of the child’s medical condition and future. Instead, parents wanted information given through one-on-one conversations in which medical terminology, parent education pamphlets, procedures, and recovery were explained to them by a nurse or physician who took the time to assess their understanding and answer questions. As time progressed, grieving also encompassed a parental acknowledgement that they might have to amend expectations for their child’s recovery. Parents commonly felt prolonged sadness, realizing that some of the changes they were witnessing in their child were likely permanent and that their child and family would chronically face negative attitudes of certain others (Roscigno & Swanson, 2011).

Grieving for the Child I Knew

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Running on Nerves

This, the most prevalent theme throughout the parents’ narratives, described the many internal and external sources of stress that parents encountered continuously. Remaining available to meet the physical and psychological needs, potential or actual, of their injured child, parents often neglected caring for their own needs. For example, one parent described resisting treatment for personal injuries incurred when her child was injured. Others spoke of neglect of personal hygiene and wearing the same clothing day after day. Parents admitted communication breakdowns, lack of understanding of TBI, confusion about medical terms, and differences in values pertaining to their child’s future opportunities. They often felt providers were in a rush, and those that did take the time to explain and answer questions were appraised as caring individuals who stood out among others. Parents also realized that they needed to use all of their own resources to gather information, and that health care providers could not be their sole source due to concerns that the information professionals provided seemed at times somewhat biased and only focused on a medical or statistical perspective. From hospitalization through integration back into the community, parents described a clash of cultures: “Parents believed that others did not truly understand what it is like to parent a child following TBI, or appreciate how the social environment also shapes the family’s experiences” (Roscigno & Swanson, 2011, p. 1419).

Grappling to Get What My Child and Family Need

Parents described the bond with their children as providing the strength to advocate for the child, to protect the child’s whole person, and to provide their child with the best possible future. Parents often felt that providers in whom they had entrusted their child’s care were willing to give up too quickly or were too narrowly focused on what their child needed. Parents longed for human-to-human interactions with providers and for the opportunity to participate in decision making for their child. Said one parent: “They should know that parents actually aren’t sitting there, waiting for you to fix the problem. They actually often want to be part of the process of bringing their loved one to health” (Roscigno & Swanson, 2011, p. 1420). On the other hand, some parents described interactions with providers who showed compassion, caring, and an eagerness to be supportive in whatever ways they could. When returning to their communities, parents learned early on that they had to monitor and sometimes manipulate the many-layered environments within which their child interacted. Some parents discussed how family issues (e.g., spousal reactions and role changes; financial and employment concerns; varied sibling needs) as a whole were not addressed either during the acute-care phase or when they returned home. Parents also spoke of the desire to connect with other families having a child with a brain injury, believing those with similar experiences would understand and be helpful to them in ways that others could not.}

Communication Challenges

Study findings highlighted the importance of health care provider conversations with parents, particularly in early acute care. Roscigno and Swanson (2011) noted strong language tones and detailed provocative stories in the meta-communication of parents of children following severe TBI. These parents often felt constrained and misunderstood. Parents of children with moderate TBI most often felt understood, but gave vague specifics about what was helpful when probed, signaling that there was something different about each group’s subjective orientation to the early acute care talk experiences and places.

Based on these observations, Roscigno, Savage, Grant, and Phillipsen (2013) conducted a secondary analysis of the data to achieve a preliminary understanding of the expectations of 27 parents of children with severe TBI from the Roscigno and Swanson (2011) study. They reported the common talk factors (physical, psychological, cultural, and political) that parents believed shaped their identities in the early acute stage period: a) physical access to the child, which is where pertinent information was obtained; b) regular discussions with key personnel; c) updated information provided and explained; d) differing expectations for talk in this context (e.g., culturally insensitive experiences created by the timing and prioritizing of talk important to the provider or hospital over talk important to the family); and e) perceived parental involvement in decisions. Roscigno and colleagues (2013) found that parents perceived the organization and nature of providers’ talk positively or negatively early on in the acute care setting, a factor that influenced how they viewed these settings as either supporting them and decreasing their workload, or discounting them and increasing the workload, required for getting their needs met.

The acute care setting following TBI presents significant challenges to good communication between health care professionals and parents. Interpersonal skills are often minimized as high-level technology skills needed to address complex injuries become a priority for providers. Commonly, physicians, nurses, and the many other team members involved have not received adequate preparation on how to manage their own and others’ difficult emotions. Further, considering the many divergent disciplines involved in care for the child and...
family, a lack of organizational structures to promote interdisciplinary communication resulting in a unified message to the family is not uncommon (Boos Okah, Swinton, Wolff, & Haney, 2010). Further, team members may avoid communicating with parents in order to protect themselves from chronic exposures to encounters where they assess there is no good outcome or good news to report (Meadors & Lamson, 2008).

Parents have a great deal of complex information to absorb at a time when their cognitive, emotional, and behavioral states make mental processing difficult. Descriptions and images of procedures that seem barbaric (e.g., drilling holes in their child’s skull, freezing bone flaps), and discussions of possible negative outcomes, can prove overwhelming (Roscigno et al., 2013). Never the less, an abundance of research findings over the years supports the fact that one of the most pressing needs for parents in these critical care settings is honest and accurate information (Farrell, 1989; Jee et al., 2013; Kasper & Nyamathi, 1988). How information is presented is of critical importance.

The coping strategies that parents use during their child’s acute care depend on a variety of factors, among them, individual and family coping styles. However, one coping strategy long identified as common in pediatric intensive care settings remains important to parents of children with TBI today: believing that their child is receiving the best care possible (Miles & Carter, 1985). Holding such a belief requires trust in the individuals providing that care; culturally competent, effective, and timely communication with parents is known to be a critical factor in building these trusting relationships (DeLomos et al., 2010).

The early hours, days, and weeks following TBI are filled with fear and uncertainty. According to Coulter (2002), the ability to emotionally connect with a parent in a time of such vulnerability is considered one of the most important traits expected of health care professionals. Despite the many challenges in the acute care phase, nurses can play a significant role in helping parents navigate this difficult time. Roscigno and colleagues (2013) call for a) creating mechanisms by which all providers and the parents can be informed of and have input into the plan of care; b) developing a means for provider disagreement to be discussed away from the family so that a unified message is given to parents; and c) assuring a complete understanding among early acute care providers regarding how their talk about processes or policies can affect parents’ perceptions of the caring or helpful nature of early acute care settings. Building policies and practices on a better understanding of the attitudes, beliefs, notions, and cultural expectations of family members can have both immediate and long-term positive outcomes for the child, parents, and the family as a whole.

References

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Goal
To provide an overview of parents’ perspectives when caring for their child with a traumatic brain injury.

Objectives
1. Explain the burden of care on parents of children with traumatic brain injury.
2. Discuss the experiences of parents of children with traumatic brain injury.
3. List three ways nurses and other health care providers can help parents navigate the acute care stages of their child’s traumatic brain injury.

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